

RD-A185 565 TUMOR REGISTRY FOLLOW-UP AT ARMY MEDICAL CENTERS(U)
ARMY HEALTH CARE STUDIES AND CLINICAL INVESTIGATION
ACTIVITY FORT SAM HOUSTON TX K P DEUSTER 03 JUN 83

TUMOR REGISTRY FOLLOW-UP AT ARMY MEDICAL CENTERS(U)
ARMY HEALTH CARE STUDIES AND CLINICAL INVESTIGATION
ACTIVITY FORT SAM HOUSTON TX K P DEUSTER 03 JUN 83

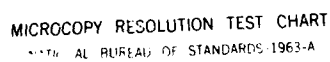
1/1

UNCLASSIFIED

F/G 5/2

NL

[illegible]



MICROCOPY RESOLUTION TEST CHART
NATIONAL BUREAU OF STANDARDS-1963-A

AD-A185 565

DTIC FILE COPY

2

TUMOR REGISTRY FOLLOW-UP AT ARMY MEDICAL CENTERS

Graduate Research Project

Conducted at Walter Reed Army Medical Center

Washington, D.C.

and

Submitted to the Faculty of

Baylor University

in Partial Fulfillment of the

Requirements for the Degree

of

Master of Health Administration

DTIC
ELECTE
OCT 06 1987
S D

DISTRIBUTION STATEMENT

Approved for public release
Distribution Unlimited

by

Major Kathryn P. Deuster, ANC

3 June 1983

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1a. REPORT SECURITY CLASSIFICATION Unclassified			1b. RESTRICTIVE MARKINGS		
2a. SECURITY CLASSIFICATION AUTHORITY			3. DISTRIBUTION / AVAILABILITY OF REPORT Approved for public release; Distribution Unlimited		
2b. DECLASSIFICATION / DOWNGRADING SCHEDULE					
4. PERFORMING ORGANIZATION REPORT NUMBER(S) 7 - 87			5. MONITORING ORGANIZATION REPORT NUMBER(S)		
6a. NAME OF PERFORMING ORGANIZATION U.S. ARMY-BAYLOR UNIVERSITY GRAD PGM IN HEALTH CARE ADMIN		6b. OFFICE SYMBOL (If applicable) HSHA-IHC	7a. NAME OF MONITORING ORGANIZATION		
6c. ADDRESS (City, State, and ZIP Code) Ft Sam Houston Tx, 78234-6100			7b. ADDRESS (City, State, and ZIP Code)		
8a. NAME OF FUNDING / SPONSORING ORGANIZATION		8b. OFFICE SYMBOL (If applicable)	9. PROCUREMENT INSTRUMENT IDENTIFICATION NUMBER		
8c. ADDRESS (City, State, and ZIP Code)			10. SOURCE OF FUNDING NUMBERS		
			PROGRAM ELEMENT NO.	PROJECT NO.	TASK NO.
			WORK UNIT ACCESSION NO.		
11. TITLE (Include Security Classification) TUMOR REGISTRY FOLLOW-UP AT ARMY MEDICAL CENTERS					
12. PERSONAL AUTHOR(S) Kathryn p. Deuster, Author					
13a. TYPE OF REPORT Thesis		13b. TIME COVERED FROM July 82 TO June 83		14. DATE OF REPORT (Year, Month, Day) 3 June 1983	
15. PAGE COUNT 86					
16. SUPPLEMENTARY NOTATION					
17. COSATI CODES			18. SUBJECT TERMS (Continue on reverse if necessary and identify by block number)		
FIELD	GROUP	SUB-GROUP	Hospitals; healthcare; medical information systems; tumor registry, <i>theses</i> ←		
19. ABSTRACT (Continue on reverse if necessary and identify by block number) Because an accredited tumor registry program contributes positively to the level of patient care delivered within Army hospitals, the Army Medical Department has supported the accreditation of its tumor registries by the American College of Surgeons. While accreditation is desirable, the accreditation requirement of a 90 percent follow-up rate is difficult for Army Healthcare Facilities because of the mobility of the beneficiary population. While the American College of Surgeons is sympathetic to the Army's unique situation, it is not willing to grant an exception to the standards. Thus, this study attempted to develop a protocol which would exceed the College of Surgeons 90 Percent follow-up rate.					
20. DISTRIBUTION / AVAILABILITY OF ABSTRACT <input checked="" type="checkbox"/> UNCLASSIFIED/UNLIMITED <input type="checkbox"/> SAME AS RPT. <input type="checkbox"/> DTIC USERS			21. ABSTRACT SECURITY CLASSIFICATION		
22a. NAME OF RESPONSIBLE INDIVIDUAL Lawrence M. Leahy, MAJ, MS			22b. TELEPHONE (Include Area Code) (512) 221-6345/2324		22c. OFFICE SYMBOL HSHA-IHC

ACKNOWLEDGMENTS

Sincere appreciation is extended to Sergeant First Class James F. Varian, NCOIC of the Walter Reed Army Medical Center Tumor Registry for his encouragement and help throughout the project. The resident wishes to acknowledge the cooperation and assistance of Major Jerry L. Scott, USAF and Lieutenant Commander Thomas A. Grimes, USN of the Defense Enrollment Eligibility Reporting System. Last, the resident wishes to thank all of the Tumor Registrars who provided information for the study.



Accession for	
NTIS	✓
DTIC	
USCIB	
Other	
By	
Date	
File	
Ref	
A-1	

TABLE OF CONTENTS

ACKNOWLEDGMENTS	ii
Chapter	
I. INTRODUCTION	1
Conditions Which Prompted This Study	1
Problem	5
Objectives	5
Criteria	5
Assumption	6
Limitations	6
Literature Review	6
Research Methodology	9
Footnotes	15
II. DISCUSSION	17
Other Registries	17
DEERS	20
Letter Sample	22
Telephone Sample	23
Combination Letter and Telephone Sample	23
New Follow-Up Form	24
Footnotes	25
III. CONCLUSIONS AND RECOMMENDATIONS	27
Conclusions	27
Recommendations	28
APPENDIX	
A. OTHER TUMOR REGISTRIES	30
B. NAVY FOLLOW-UP POSTCARD	43
C. DEERS CORRESPONDENCE	45

APPENDIX

D. DEERS SAMPLE	49
E. WRAMC FOLLOW-UP FORM	51
F. LETTER SAMPLE	55
G. TELEPHONE SAMPLE	60
H. COMBINATION LETTER AND TELEPHONE SAMPLE	65
I. NEW FOLLOW-UP FORM	70
J. PROJECT FINDINGS	72
K. FITZSIMONS FORM	74
L. MILITARY FOLLOW-UP SOURCES	76

CHAPTER I

INTRODUCTION

Conditions Which Prompted This Study

The importance of accreditation of the Tumor Registry program of Army Medical Centers is recognized and supported by the Army Medical Department. This is apparent by the willing utilization of Army Medical Department resources for the initiation of computerization of the Tumor Registry at Walter Reed Army Medical Center (WRAMC) by Tri-Service Medical Information Systems Army Support Activity. This was accomplished in order that the registry might be in a more favorable position for its 1982 accreditation visit by the American College of Surgeons (ACS). As recently as September 1982, the U.S. Army Health Services Command (HSC) adopted the computerized Tumor Registry System developed at Dwight David Eisenhower Army Medical Center as the HSC Standard Tumor Registry System. This system will be extended for use at other Army Medical Centers.¹ In addition, HSC has employed a full-time civilian Tumor Registry Staff Officer to oversee HSC policy and advise individual Army registries, as further evidence of the Army Medical Department's commitment to Tumor Registry accreditation of its Medical Centers.

Army Medical Centers are involved in the treatment of many

active duty and retired service members and their dependents diagnosed with cancer. "About 56 million Americans now living will eventually have cancer--one in four, according to present rates."² Advancements in medical science have resulted in chemotherapy protocols and radiation treatments leading to the cure of some malignancies while prolonging the length and/or improving the quality of life in others.³

An accredited tumor registry program contributes positively to the level of patient care delivered within an Army medical center. Cancer management is improved by the collection, organization, analysis, and interpretation of data in the tumor registry. This information can then be used for patient treatment planning, physician education, and research.⁴ Voluntary accreditation by the ACS not only enhances the medical education programs at these facilities, but is also a requirement for the accreditation of several of the Army surgical residency programs. For these reasons tumor registry accreditation is desirable and beneficial for all Army medical centers.

For each patient entered in the registry, the ACS expects that follow-up information will be collected at least on a yearly basis until the date of death of the patient.⁵ The minimal standard for an approved tumor registry is a 90 percent follow-up rate.⁶

An inadequate follow-up rate reduces the effectiveness of a tumor registry program and may also result in nonaccreditation of an Army medical center tumor registry. Follow-up is the responsibility of the tumor registry which originally accessioned the patient. For example, a cancer patient diagnosed at WRAMC must be followed by the WRAMC tumor registry. Acceptable follow-up may be obtained either by external direct patient contact or by internal access to the medical record following a hospitalization or clinic visit. However, medical record follow-up is not predictable or dependable follow-up.

Computerization of an Army medical center's tumor registry increases efficiency by allowing better access to the recorded information, but it does not guarantee a 90 percent follow-up rate. A mobile military population makes follow-up particularly difficult. Frequently, Army patients are diagnosed by referral to a medical center where they receive initial treatment. They may receive follow-up treatment at distant medical facilities due to retirement in remote areas, or the permanent change of station of the sponsor for dependent patients. Even during a shortened lifetime, some military cancer patients can have numerous address changes. Due to the frequent address changes, the opportunity to lose track of these patients is great; therefore, follow-up is a very real problem for

Army medical center tumor registries.

WRAMC, the largest Army medical center, has an accession of approximately 750 new patients in the tumor registry annually. In 1981, the latest year for which complete figures are available, there were 803 patients accessioned. The follow-up rate for that year group, which includes 96 known deaths, was only 61.5 percent. In fact, WRAMC has never accomplished a 90 percent follow-up rate. Of the 22,522 patients accessioned in the WRAMC tumor registry since its inception in 1950, 12,509 are supposedly living and, therefore, require yearly follow-up.

Despite its failure to attain a 90 percent follow-up rate, the WRAMC tumor registry received verbal assurance of approval at the conclusion of its accreditation inspection by ACS. This apparent waiver is presumably due to recognition of current intense efforts to computerize and update the registry files. Tremendous energy is being expended to correct years of neglect with the intent to create a truly outstanding registry. Less than a 90 percent follow-up rate will be unacceptable when WRAMC is again inspected by ACS.

A protocol to improve the follow-up rate of Army medical center tumor registries would help insure ACS accreditation and, at the same time, would also contribute to survivability studies.

Such a protocol would be generally adaptable to all Army medical centers to increase their follow-up rates.

Problem

The problem addressed by this study was the determination of the most cost effective procedures for increasing WRAMC's Tumor Registry follow-up rate consistent with the guidance provided by the ACS.

Objectives

1. To evaluate the relative effectiveness and cost of utilizing various mechanisms to maintain routine external follow-up.
2. To develop a specific external follow-up protocol which can be adapted by all Army medical center tumor registries.

Criteria

1. A 90 percent follow-up rate was required.
2. All routine follow-up efforts were completed within 60 days from the date the project commenced.
3. A 90 percent confidence level was used to determine the research sample sizes.
4. Cost effectiveness was determined by the method which

produced the highest rate of follow-up for the lowest cost within a 60 day time frame.

Assumption

No assumption was made in this study.

Limitations

Only WRAMC Tumor Registry patients with complete social security numbers were used in this project, since medical records are accessible only by a social security number or a hospital registration number. Name alone is insufficient identification when dealing with a potential information source such as the Defense Enrollment Eligibility Reports Systems (DEERS).

The tumor registry population for this project was limited to those patients accessioned in 1981 because this was the most current known population for which follow-up should have been completed in 1982. Obituary notices were not utilized in this project since they were both unavailable and impractical for the geographically dispersed military patient population followed by the WRAMC Tumor Registry.

Literature Review

Numerous professional articles are readily available concerning cancer and its many implications; however, few articles or

publications are written specifically addressing the hospital tumor registry. Generally, the articles located through Med-Line computer services address computerization of the registry or discuss such topics as the importance and benefits of a registry. Good examples of the latter are: "Hospital Cancer Programs and Registries: What Good are They?" by Walter Lawrence, Jr. and "The Benefits of a Hospital Cancer Program" by Henry P. Russe and Vida M. Peterson. Such articles do not discuss tumor registry techniques.

The National Tumor Registrars Association, established in 1974, publishes a monthly professional journal, The Abstract. A review of these journals since 1978 reflects the growth of the emerging professional tumor registrar. Increasingly sophisticated demands and requirements of the ACS and users of the registry are readily apparent.⁷ Even so, the resident found only two articles that specifically addressed follow-up. One of the articles was very general while the other article described a patient wallet card used by the Community Hospital of San Gabriel, California. The card reminds the patient of the need for annual checkups and helps keep the tumor registry records up-to-date. The wallet card has been very well accepted by physicians and patients, and apparently has improved follow-up.⁸

The American College of Surgeons is the primary source of technical literature on the operation of tumor registries. Techniques of casefinding, staging, and abstracting are described in great detail in the Cancer Program Manual: A Supplement on the Tumor Registry. Follow-up is a critical element of the Cancer Program, yet it is addressed only in terms of requirements and guidelines. Both the Cancer Program Manual: A supplement on the Tumor Registry and the World Health Organization's book Cancer Registration and Its Techniques describe routine, hospital generated, sources of follow-up such as medical records, pathology reports, and outpatient visits. The literature does little more than list possible tools such as form letters and the telephone for directly contacting patients. Additional sources of information mentioned are other registries and obituary notices. Most military patients are unknown to civilian registries and obituary notices are an impractical tool for Army medical centers, since patients frequently do not reside in the immediate vicinity. A request by the resident to the American College of Surgeons for specific literature on follow-up produced a copy of the Cancer Program Manual and a handful of articles which mentioned follow-up.

In all probability, the dearth of detailed information on follow-up is due to two facts. First, the civilian community does

not have a significant problem with follow-up. The ACS states that most patients are readily traced for follow-up.⁹ Second, most civilian registries generally do not contact patients directly but work through the private physician. It is very important that the registrar have physician permission to contact patients directly.¹⁰ The physician is often key to successful civilian follow-up.

The Army tumor registry programs differ from their civilian counterparts in several respects. There is a significant problem in maintaining follow-up in the mobile military community. In the Army, the tumor registry, not the physician, is the consistent element in maintaining follow-up. Therefore, tumor registrars may directly contact all patients accessioned to the registry. None of the literature reviewed by the resident described a successful and efficient protocol for direct patient follow-up.

Research Methodology

Three separate activities were involved in this project. First, all other Army medical centers located in the continental United States were telephonically surveyed in order to obtain information about current follow-up protocols. In essence, the resident wanted to ascertain which protocols were effective. Each

tumor registrar was asked a series of questions:

1. When was your registry started?
2. How many patients are in your registry?
3. How many of those patients are currently living?
4. How many patients did you enter in the registry last year?
5. What is your follow-up rate?
6. How much time do you devote to follow-up?
7. When do you first make contact with a patient?
8. Do you mail repeat letters if there is no response from the patient?
9. Do you utilize the telephone for follow-up?
10. What do you do when you lose a patient to follow-up?

In order to broaden the survey base, the resident also visited the tumor registries of two Navy medical centers, one Air Force medical center, and two civilian institutions. The University of Maryland Hospital was the largest registry visited; the Arlington Hospital Tumor Registry was the only registry surveyed which participated in a central registry. The Arlington Hospital, a small hospital, has a two-way flow of information with the state-operated central registry. In the process, the Arlington Hospital benefits from the state's computer support. Each registrar was asked the

same ten questions used to survey the Army registries.

The second action was to investigate the possibility of obtaining locator help from the new Defense Enrollment Eligibility Reporting System (DEERS). DEERS is a Department of Defense program directed by Congress to maintain an up-to-date data base on the Uniformed Services population. The data base includes active duty personnel, retirees, surviving spouses, and dependents from all seven Uniformed Services. Active duty military personnel and retirees entitled to retirement pay are automatically enrolled in the data base from existing personnel and finance records. Surviving spouses must enroll themselves while all dependents must be enrolled by their sponsor. Part of the information collected with each enrollment is a current address.¹¹ Access to the DEERS addresses for patients with whom the tumor registry has lost contact would improve the follow-up rate.

The DEERS program office in Washington, D.C. was approached by the resident about the possibility of providing the tumor registry with needed addresses. Since the registry had accumulated 503 follow-up letters returned because of incorrect addresses, the resident chose a sample from these patients. Sixty patients would have provided an adequate sample size to determine the feasibility of obtaining addresses from the DEERS program. The number was determined by

using the following finite sample size formula:

$$\text{sample size} = \frac{N Z^2 pq}{d^2 (N-1) + Z^2 pq} \quad 12$$

A 90 percent confidence level (Z value of 1.645) was used.

The resident was unwilling to accept an allowable error of more than .10. Because a search of the DEERS data base had not previously been accomplished, a conservative estimate was made that at least half of the names would be in the system (.5) and half would not (.5).

$$\text{sample size} = \frac{503 (1.645)^2 (.5) (.5)}{(.10)^2 (502) + (1.645)^2 (.5) (.5)} = 59.7353 \quad \text{patients}$$

The DEERS personnel felt that a sample size of 60 was too small and requested that 200 names be used. In order to insure DEERS' cooperation and participation the returned letters were numbered and a Table of Random Units was used to select a sample of 200 names.¹³ These names were sent to the DEERS support office in Monterey, California, the depository for all addresses.

The third action was to conduct research to determine the most cost effective methods for increasing the tumor registry follow-up: (A) follow-up via form letter, (B) follow-up by telephone, and (C) follow-up by the combination of form letter and telephone.

The project population consisted of the 309 patients accessioned in the WRAMC Tumor Registry in 1981 who did not receive annual follow-up in 1982. The previously described finite sample size formula was used to determine a patient sample size of 56. A 90 percent confidence level was used. The resident was unwilling to accept an allowable error of more than 10 percent. Since WRAMC has historically given a low priority to follow-up, there was no accurate indication of the percentage of responses and nonresponses to follow-up derived directly from patients. Therefore, the assumption was made of an even split of responses and nonresponses. The formula calculation was 55.6477, a sample size of 56 patients.

By using a random units table, 56 patients were selected and sampled via form letter. Addresses were obtained from the registry files and/or in-patient records. All envelopes displayed a "please forward" statement. A preaddressed and stamped return envelope was enclosed with each form letter. Since some patients need a reminder, a repeat letter was sent after 30 days if there had been no response from the initial request. DEERS' assistance was sought for patients whose letters were returned due to incorrect addresses.

The cost per letter was determined by the following factors: the average amount of time required for letter preparation, the

average salary of an employee who would perform the task, the postage, and the cost of the forms and the envelopes.

A second sample of 56 different patients was randomly selected and contacted via telephone. Telephone numbers were obtained from registry files and/or in-patient records. The telephone directory assistance service was utilized as necessary and each newly provided telephone number was called. All telephone calls were made in the same 60 day time period used for the letter sample. DEERS was consulted for all patients in the telephone sample who had become lost to follow-up.

The cost per telephone call was determined in the same manner as the cost per letter. The average telephone cost, based on the Wide Area Telecommunication Service (WATS) was used since the majority of the Army medical centers utilize WATS. The WATS costs were provided by a representative of the Defense Telephone Agency.¹⁴

A third sample of 56 randomly selected patients was utilized as a combined letter and telephone call sample. Addresses and telephone numbers were obtained in the same manner previously described. An initial letter was sent. If after 30 days there was no response, an attempt was made to contact the patient via telephone. The average cost of a positive follow-up included the costs of the letter, telephone call(s), and labor.

For both letters and telephone calls, the cost per attempt times the number of attempts made to achieve one follow-up equaled the total cost of one follow-up. All individual total costs were averaged to determine an average cost per follow-up. The resident compared the success rates and the average costs of the three samples.

Footnotes

¹"HSC Standard Tumor Registry System," CG HSC Bulletin, October, 1982, p. 11.

²Henry P. Russe and Vida M. Peterson, "The Benefit of a Hospital Cancer Program," The Hospital Medical Staff 11, No. 2 (February 1982): 12.

³Charles R. Smart, "The Commission on Cancer," Bulletin, American College of Surgeons 65, No. 9 (September 1980): 4.

⁴Russe and Peterson, p. 13.

⁵Evelyn M. Shambaugh, ed., Self-Instructional Manual for Tumor Registrars, Book One (Washington, D.C.: National Institutes of Health, 1980), p. 58.

⁶Robert J. McKenna, "Goals for a New Decade," Bulletin, American College of Surgeons 65, No. 9 (September 1980): 7.

⁷Evelyn Shambaugh, "President Notes Accomplishments, Goals," The Abstract 7, No. 1 (November 1980): 5, 8; Marilyn C. Hurst, "Presidential Message," The Abstract 9, No. 1 (August 1982): 3-4.

⁸B. E. Thiele, "Utilizing the Tumor Registry," The Abstract 5, No. 4 (July 1978): 1; Dawnelle Chapman, "Patient Wallet Card," The Abstract 7, No. 1 (November 1980): 12.

⁹American College of Surgeons, Cancer Program Manual: A Supplement on the Tumor Registry (Chicago: American College of Surgeon's Commission on Cancer, 1981), p. 10.

¹⁰Ibid., p. 9.

¹¹Defense Enrollment Eligibility Reporting System, DEERS Fact Sheet, April 1983, p. 1-6; Department of Defense, DOD 1341.1M DEERS Program Manual (Washington, D.C.: Government Printing Office, May 1982), p. 1-8.

¹²Wayne W. Daniel, Biostatistics: A Foundation for Analysis in the Health Sciences, 2d ed. (New York: John Wiley & Sons, 1978), pp. 142-45.

¹³Samuel M. Selby, ed., CRC Standard Mathematical Tables, 19th ed. (Cleveland, Ohio: The Chemical Rubber Co., 1971), pp. 622-23.

¹⁴Interview with Ginny Hughes, Communication Specialist for the Defense Telephone Agency, Washington, D.C., 9 May 1983.

CHAPTER II

DISCUSSION

Other Registries

Talking to the tumor registrars was both informative and enjoyable. (See Appendix A.) It was readily apparent that these ladies are very dedicated professionals who are working to ensure continued approval of their registries. WRAMC is the only continental (CONUS) Army medical center registry with less than a 90 percent follow-up. Due to its large patient census, WRAMC enters significantly more patients in its registry each year than do the other Army facilities. Both Dwight David Eisenhower Army Medical Center (DDEAMC) and William Beaumont Army Medical Center (WBAMC) accession approximately 300 patients each year. DDEAMC maintains a 96 percent follow-up rate while WBAMC is slightly less at 94 percent.¹ Fitzsimons Army Medical Center (FAMC) has a 92 percent rate; FAMC enters approximately 470 new patients in the registry each year.² Brooke Army Medical Center, Madigan Army Medical Center and Letterman Army Medical Center each have a 90 percent follow-up rate.³ The number of patients they accession ranges from 330 to 460.

The follow-up rate for the three Air Force and Navy

registries was greater than 90 percent. The Malcolm Grow USAF Medical Center has a rate of 95 percent; approximately 500 patients are accessioned yearly.⁴ The National Naval Medical Center at Bethesda has a long established registry which yearly gains 500 new patients.⁵ Their follow-up rate is 92 percent. The Naval Regional Medical Center at Great Lakes only enters 250 patients each year; their follow-up rate is 98 percent.⁶

The two civilian hospitals manage their follow-up well. The Cancer Registry of the University of Maryland in Baltimore was the largest registry visited by the resident. Even though they do not have the advantage of automation, volunteer help assists this registry in maintaining a 90 percent follow-up while accessioning approximately 1,000 new patients each year.⁷ The Arlington Hospital in Virginia maintains a 97 percent follow-up while entering 600 patients to the registry each year. Much of their follow-up is accomplished through the physicians.⁸

Every registrar reported that follow-up is an ongoing process. Each registry uses form letters or postcards. Letterman Army Medical Center has a postcard follow-up form. However, the form is not entirely satisfactory and is currently under revision. The National Naval Medical Center routinely uses a folded postcard arrangement that provides both privacy for the patient's information

and convenience for the registry personnel. (See Appendix B.)

All other registries use form letters. Most registries send second and third follow-up letters when necessary. Response is better when a differently worded letter is used each time.

When a letter is returned due to an incorrect address, the patient's medical record is the first source of possible information for all of the registries. Sometimes the chart will indicate which medical facility will follow the patient or that he might be moving to a specific place. Every registry routinely utilizes other registries and medical treatment facilities as well as governmental and civilian agencies to assist in locating registry patients. Most of the registries with very good follow-up do not hesitate to use the telephone to contact patients.

In surveying the different registries it became readily apparent to the resident that there were several factors which contribute to a better than 90 percent follow-up rate. The tumor registrar in the Air Force and Navy hospitals is highly visible. There is good communication from both medical records and the clinics to the registry; therefore, internal follow-up is high. Unfortunately, the majority of the Army registries seem to receive poor clinic support. The registries which make early patient contact and/or obtain a fact sheet with permanent addresses have a

higher follow-up rate. Lastly, the time dedicated to follow-up is critical to maintaining a follow-up. It appears that registries which devote a significant amount of time to follow-up have a significantly more successful follow-up rate. The registries, military and civilian, which have better follow-up rates devote a specific person to the task. Generally, it is a full time job. A person dedicated to follow-up soon becomes an expert at tracking patients who have become lost to the registry. All of the registrars contacted agreed that follow-up is a very time-consuming process.

DEERS

The DEERS program is a very large and complex system involving the seven Uniformed Services and approximately ten million records. Although the enrollment of beneficiaries living within the continental United States was completed in September 1982, the program is still in an implementation stage. Changes and improvements are constantly being made to the computer programs.

The DEERS personnel were very receptive to providing addresses. Their attitude was very positive and their manner most cooperative. However, the Washington office overestimated the ability of the Monterey office. The addresses are not yet in the

computer; therefore, each address was obtained from a hard copy file. Finding one specific file out of ten million was a laborious and time-consuming process. The DEERS Support Office in Monterey required four months to process 161 names in the original 200 name sample. They are currently searching for the remaining 39 names. (See Appendix C.)

Of great significance to the WRAMC Tumor Registry is the fact that the DEERS program was able to identify that 23 patients or 11.5 percent of the sample were deceased. Of the remaining 138 names which were processed, DEERS was able to provide either a home or duty address for 103 patients. (See Appendix D.) Many of the follow-up letters were not mailed until late April, therefore, the successful follow-up rate for these patients is not yet known. At the end of May 37 patients had been successfully contacted and 12 letters had been returned due to incorrect addresses. The successful follow-up of 60 patients previously lost to WRAMC Tumor Registry follow-up was very significant. (The identification of deceased patients was considered successful follow-up.)

Due to the fact that the addresses are not yet on the computer, the DEERS support office was unable to provide any addresses in a timely manner for the letter and telephone samples. A one-month time frame is impractical for their operation. However, due

to the request of the resident and the legitimacy of the need, the Monterey support office is improving their current procedure for providing addresses. They are committed to providing WRAMC support on a quarterly basis.

Due to new CHAMPUS requirements, addresses (the street and zip code) are beginning to be entered into the computer. Although this will be a very lengthy process, the future is indeed positive. In time, any tumor registry will be able to obtain addresses listed in the computer by using the local medical facility DEERS' terminal. In the meantime, the support office is perfecting their manual system.⁹

Letter Sample

A total of 85 form letters were mailed to 14 states including the District of Columbia; 33 patients or family members completed the forms and returned them to the tumor registry. (See Appendix E.) Twenty-two individuals answered the first letter and another 11 patients responded to the second letter mailed one month after the first request. The average cost for a successful letter follow-up was \$1.97. (See Appendix F.) Unfortunately, the success rate was only 39 percent.

Eight letters were returned by the post office due to incorrect addresses.

Telephone Sample

A total of 94 telephone calls were made; 28 patients were contacted. On several occasions follow-up information was provided by the spouse. When there was no answer to repeated phone calls made during the day, calls were made in the evening and on a Saturday morning. A total of seven patients received four or more telephone calls. The repeated calls were generally nonproductive since only two contacts were made for those seven patients. (See Appendix G.) The average cost for a successful telephone follow-up was \$2.11. The success rate was a disappointing 30 percent.

Twenty-six telephone numbers which equaled almost one-half of the sample, were incorrect. In each instance directory assistance was sought with limited success, providing only two new telephone numbers.

Combination Letter and Telephone Sample

A total of 103 follow-up attempts was made. Each of the 56 patients received a letter; one month later 47 telephone calls were made to those patients who had not responded to the letter. Twenty patients answered the letter and another 13 individuals were contacted by telephone. Several spouses provided the required follow-up information over the telephone. The average cost for a successful

follow-up was \$2.11. (See Appendix H.) The success rate was 32 percent.

The total of incorrect addresses and telephone numbers was high since five letters were undeliverable by the post office and 17 phone numbers were incorrect. Directory assistance was requested for each incorrect number but failed to provide any current telephone numbers.

New Follow-Up Form

Originally, the resident intended to devise a new tumor registry form for telephone follow-up. However, after conducting follow-up with the current WRAMC form and discussing follow-up forms with several tumor registrars, it became apparent that a WRAMC form dedicated solely to telephone follow-up would be impractical. The usage factor would not justify such a form.

Telephone follow-up can easily be recorded on the regular follow-up form; a rubber stamp can be used to indicate that it was a telephone contact. The staff person obtaining the information would sign the form and indicate the source of the information.

Many of the current follow-up forms, including the WRAMC form, request insufficient patient information. The resident reviewed the computer abstract for the minimal information required by ACS and designed a new follow-up form. (See Appendix I.)

At the present time, WRAMC encloses three forms in each follow-up envelope: an introductory letter, the follow-up form, and a Privacy Act Statement. In order to facilitate the preparation of the follow-up letters, the follow-up form could be printed on the back of the introductory letter. Such an arrangement would decrease the required number of forms to two. Several other registries find this arrangement very satisfactory.

Footnotes

¹Interview with Linda Howland, Tumor Registrar, Dwight David Eisenhower Army Medical Center, Fort Gordon, Georgia, 18 April 1983; Interview with Vera Gunper, Tumor Registrar, William Beaumont Army Medical Center, El Paso, Texas, 12 May 1983.

²Interview with Dell Benabese, Tumor Registrar, Fitzsimons Army Medical Center, Aurora, Colorado, 8 April 1983.

³Interview with Dorothy Escobedo, Tumor Registrar, Brooke Army Medical Center, Fort Sam Houston, Texas, 12 May 1983; Interview with Chris Randadzo, Tumor Registrar, Madigan Army Medical Center, Tacoma, Washington, 6 April 1983; Interview with Nina Saharoff, Tumor Registrar, Letterman Army Medical Center, San Francisco, California, 8 April 1983.

⁴Interview with Patricia Becker, Tumor Registrar, Malcolm Grow USAF Medical Center, Andrews Air Force Base, Camp Springs, Maryland, 18 March 1983.

⁵Interview with Loretta Hinitz, Tumor Registrar, National Naval Medical Center, Bethesda, Maryland, 24 February 1983.

⁶Interview with Ruth Callahan, Tumor Registrar, Naval Regional Medical Center, Great Lakes, Illinois, 25 February 1983.

⁷Interview with Acquilla Wingfield, Cancer Registrar, University of Maryland Hospital, Baltimore, Maryland, 24 March 1983.

⁸Interview with Beverly Kiley, Tumor Registrar, the Arlington Hospital, Arlington, Virginia, 18 April 1983.

⁹Interview with Thomas A. Grimes, LCDR, MSC, USN, Chief, Field Support Division, DEERS Support Office, Monterey, California, 25 May 1983.

CHAPTER III

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

With increased significance being given to the continued accreditation of the tumor registry program of Army medical centers, it is important that the registries meet or exceed the 90 percent follow-up requirement of the ACS. Studies conducted at WRAMC to evaluate follow-up effectiveness and cost using form letters, telephone calls, and a combination of letters and telephone calls indicated that form letters were the most effective and least costly method for direct patient contact follow-up.

Although the number of successful follow-up contacts was 33 for both the letter sample and the combination letter and telephone sample, the percentage of successes was greater and the average cost per successful follow-up contact was less for the letter sample. The percentage of successes was 39 for letters and 32 for the combination sample; the average cost per successful attempt was \$1.97 for letters and \$2.11 for the letter and telephone combination. The actual cost per letter attempt was 9 cents more but the average cost was 14 cents less than the letter and telephone combination because more of the letter attempts were successful. The telephone

was the least effective follow-up method since it produced the smallest success rate. (See Appendix J.)

Several observations were made regarding follow-up letters. In the combination letter and telephone call sample, 20 patients or 61 percent of those who responded did so to the letter. In the letter sample, 29 or approximately one-half of the patients received a second letter; 33 percent of the replies resulted from the second letter. Many of the tumor registrars had told the resident that it was not unusual to send a second or even a third follow-up letter to patients.

Based on the WRAMC study and the good results of the registries who made early contact with patients, it would appear that more current and/or permanent addresses obtained through early patient contact would increase the response rate. The results of the study also suggest that internally generated follow-up via the clinics and the Admissions Office must be increased.

Recommendations

The recommended procedures or protocol for direct patient follow-up is as follows:

1. Obtain patient information to include one or more permanent addresses at the first clinic appointment after discharge.

A form similar to the Fitzsimons Army medical center patient-data form should be used. (See Appendix K.)

2. Routinely use form letters as the vehicle for follow-up.
3. Send the first scheduled follow-up letter in three months. Mail a second letter in 30-45 days if there has been no response.
4. Send another routinely scheduled follow-up letter in nine months. Mail a second letter in 30-45 days if there has been no response.
5. Thereafter, maintain a yearly follow-up via letter.
6. Dedicate at least one staff member to full-time follow-up.
7. Use the telephone for problem follow-up.
8. Utilize every available source to find patients who have become lost to registry follow-up. (See Appendix L for frequently used military sources of follow-up.)
9. Utilize DEERS on a quarterly basis to help locate registry patients.

APPENDIX A

OTHER TUMOR REGISTRIES

Tumor Registry

Dwight David Eisenhower Army Medical Center

Fort Gordon, Georgia 30905

Registry began in 1964.

Number of patients in the registry is 2,800.

Number of living patients in the registry is approximately 1,300.

Number of patients entered in the registry last year is approximately 300.

The follow-up rate is 96 percent.

The time devoted to follow-up is 40 hours per week.

On the patient's first clinic visit, a registration form with permanent addresses is completed for the Tumor Registry. The patient is informed that he/she will be followed by the registry. The first follow-up letter is sent one year later. Generally a second or even a third letter spaced a month apart is necessary to obtain a response. The telephone is frequently used to obtain follow-up.

The Army locator and the retired military pay officer have provided needed addresses. Voter registries have even been utilized to locate patients.

Tumor Registry

William Beaumont Army Medical Center

El Paso, Texas 79920

Registry began in 1953.

Number of patients in the registry is 5,266.

Number of living patients in the registry is approximately 2000.

Number of patients entered in the registry last year is 300.

The follow-up rate is 94 percent.

Time devoted to follow-up is 40 hours per week.

The first follow-up letter is sent in three months; the next scheduled letter is sent in nine months. Thereafter, yearly follow-up is attempted. If a patient does not respond, repeat letters are sent monthly for several months. If a telephone number is available, the patient will be contacted via telephone.

When contact is lost with the patient, physicians, other tumor registries, veteran hospitals, and the retired military pay offices often provide a new address.

Tumor Registry

Fitzsimons Army Medical Center

Aurora, Colorado 82045

Registry began in 1954.

Number of patients in the registry is 10,537.

Number of living patients in the registry is 4,920.

Number of patients entered in the registry last year is 470.

The follow-up rate is 92 percent.

Time devoted to follow-up is approximately 70 hours per week.
(Occasional volunteer help is used.)

The first follow-up letter is sent to the patient on the day of his/her discharge from the hospital. The letter is introductory in nature and requests information such as permanent addresses. Ten months later the patient receives a follow-up letter. The registry used to maintain follow-up every six months but patients "got tired" of such frequent notices. Ten month intervals seems to meet the needs of both the registry and the patients. If a letter is not answered within three months, a repeat form is sent. Three different letters will be sent. If possible, relatives and/or friends will be contacted. The telephone is frequently utilized to follow-up patients.

When a patient is "lost to follow-up," the Veteran Administration is often helpful in locating a patient. Banks will sometimes forward a letter to the patient. The Bureau of Vital Statistics provides death information.

Tumor Registry

Brooke Army Medical Center

Fort Sam Houston, Texas 78234

Registry began in 1947.

Number of patients in the registry is approximately 13,000.

Number of living patients in the registry is 5,114.

Number of patients entered in the registry last year is approximately 350.

The follow-up rate is 90 percent.

The time devoted to follow-up is 20 hours per week.

The first follow-up contact is a letter sent six months after the patient's discharge. If there is no response, a second letter is sent in three months; a third letter will be mailed three months later if necessary. Routine follow-up is obtained every six months. The telephone is used if the patient does not respond to repeated letters. As a last resort, a certified letter will be sent to a patient since the patient's signature indicates that he is living.

Next of kin frequently provide a current address. The Army locator is sometimes helpful in providing addresses.

Tumor Registry

Madigan Army Medical Center

Tacoma, Washington 98431

Registry began in 1952.

Number of patients in the registry is 7,000.

Number of living patients in the registry is approximately 3000.

Number of patients entered in the registry last year is 460.

The follow-up rate is 90 percent.

The time devoted to follow-up is approximately 10 hours per week.
(Volunteer Red Cross help is utilized when available.)

The first follow-up letter is sent in seven months. If there is no response within two months, a different form letter is mailed. The telephone is used as a last resort.

Other military tumor registries and the Army Finance Center in Indianapolis, Indiana, are frequently helpful in providing current addresses.

Tumor Registry

Letterman Army Medical Center

San Francisco, California 94129

Registry began in 1963.

Number of patients in the registry is approximately 6,000.
Number of living patients in the registry is approximately 3,000.
Number of patients entered in the registry last year is 330.

The follow-up rate is 90 percent.
Time devoted to follow-up is 25 hours per week.

The first follow-up is attempted in one year. A form postcard is sent; if there is no response from the patient within one month, a second identical form postcard is sent.

When a patient is "lost to follow-up," other tumor registries, government facilities/agencies, and telephone books are used to locate patients. When all else fails, attempts are made to contact the patient by telephone.

Although the registry personnel have very little contact with hospitalized patients, the registrar would like to start such a program so that patients would become aware of the tumor registry.

Tumor Registry

Walter Reed Army Medical Center

Washington, D.C. 20307

Registry began in 1950.

Number of patients in the registry is 22,522.

Number of living patients in the registry is 12,509.

Number of patients entered in the registry last year is
approximately 750.

The follow-up rate is 61.5 percent for the 1981 year group.

The overall follow-up rate is much less than the required 90 percent.

The time devoted to follow-up is approximately 40 hours per week.

Standard operating procedure is that patients are contacted via
form letter in one year. Reality is that follow-up has been given
a low priority; many patients receive no follow-up. Additionally,
the tumor registry does not have addresses for many of its patients.

Tumor Registry

Malcolm Grow USAF Medical Center

Andrews Air Force Base, D.C. 20331

Registry began in 1980.

Number of patients in the registry is approximately 1500.

Number of living patients in the registry is approximately 850.

Number of patients entered in the registry last year is 509.

The follow-up rate is 95 percent.

The time devoted to follow-up is approximately 30 hours per week.
(Volunteer help is utilized).

During the patient's hospitalization, the tumor registrar obtains the patient's address and information from the chart. According to Air Force regulation follow-up is performed every six months for the first year and, then, yearly. When a patient moves, regulation requires that he/she take the tumor registry information card to the next medical treatment facility.

Other Air Force hospitals often provide current information/addresses on registry patients. The Air Force and Navy locators are frequently helpful. The Social Security Administration has occasionally forwarded letters.

Tumor Registry
National Naval Medical Center
Bethesda, Maryland 20014

Registry began in 1959.

Number of patients in the registry is approximately 11,000.
Number of living patients in the registry is approximately 5,200.
Number of patients entered in the registry last year is 500.

The follow-up rate is approximately 92 percent.
The time devoted to follow-up is approximately 40 hours per week.

Many of the patients visit the Tumor Registry and become familiar with its purpose prior to their discharge from the hospital. Follow-up letters are sent after one year. Second and third repeat letters are sent every 3 months if necessary. Telephone calls are seldom made.

The military service locators and other military hospitals are the primary sources used to locate patients.

Tumor Registry

Naval Regional Medical Center

Great Lakes, Illinois 60088

Registry began in 1965.

Number of patients in the registry is approximately 3,000.
Number of living patients in the registry is approximately 900.
Number of patients entered in the registry last year is
approximately 250.

The follow-up rate is 98 percent.
The time devoted to follow-up is approximately 16 hours per week.
(Red Cross Volunteer help is utilized when available.)

The physicians send their patients to the tumor registry prior to discharge. The registrar personally meets every patient and explains the purpose of the registry. The need for follow-up is emphasized and permanent addresses are obtained. The first follow-up letter is sent after one year. If there is no response, at least three more letters will be sent at 3 month intervals. The telephone is frequently used.

Few patients become lost to follow-up but when they do, every conceivable source is utilized to locate them. Generally other registries or governmental agencies can provide the needed information. Such sources as landlords and churches can be extremely helpful.

Cancer Registry
University of Maryland Hospital
Baltimore, Maryland 21201

Registry began in 1969.

Number of patients in the registry is 11,884.

Number of living patients in the registry is 3,895.

Number of patients entered in the registry last year is 999.

The follow-up rate is 90.1 percent.

The time devoted to follow-up is 40 hours per week.

The University hospital accommodates both private and nonprivate patients. The Cancer Registry contacts the physician for information on a private patient. However, nonprivate patients are contacted directly by the registry staff. Follow-up letters are sent after twelve months and yearly thereafter. If there is no response, a repeat letter is sent one month later. The telephone is used for problem follow-up.

Relatives, friends, and neighbors frequently provide needed patient information. Telephone books and obituaries are very helpful. The State Department of Vital Statistics is the source of many death verifications.

Tumor Registry
The Arlington Hospital
Arlington, Virginia 22205

Registry began in 1979.

Number of patients in the registry is 2,669.

Number of living patients in the registry is 1,244.

Number of patients entered in the registry last year is 600.

The follow-up rate is 97.3 percent.

The time devoted to follow-up is approximately 50 hours per week.

The majority of the follow-up (70 percent) is obtained from physicians. The doctor must grant permission for the registry to contact a patient. Follow-up is initiated after one year. Form letters are utilized for both the physicians and the patients. Repeat letters are sent if there is no response. Local telephone calls are utilized for problem follow-up.

When routine sources of information fail to locate a patient, the registry seeks the help of the Department of Motor Vehicles, insurance companies, banks, labor unions, visiting nurses' associations, medicaid and medicare offices, and surrounding hospitals, nursing homes and hospices.

APPENDIX B

NAVY FOLLOW-UP POSTCARD

Dear Mrs. Deuster,

The detachable card is for the purpose of keeping an accurate record of your case in this office. A similar card will be mailed to you EACH YEAR. Therefore, we would appreciate your keeping this office advised of any change of address.

Will you kindly fill in the information requested, detach the return portion and mail it? It is postage-free for your convenience.

Thank you,

Sincerely yours,

44

Deuster, K. 142.0

DATE _____

MY PRESENT ADDRESS IS _____

ARE YOU EMPLOYED AT THE PRESENT TIME? _____

☐ FULL TIME

☐ PART TIME

WHICH OF THE FOLLOWING BEST DESCRIBES YOUR PRESENT STATE OF HEALTH:

☐ WELL

☐ IMPROVED

☐ NO BETTER

☐ WORSE

MY PRESENT WEIGHT IS _____

DATE OF LAST PHYSICAL EXAMINATION: _____

PLEASE DESCRIBE YOUR PRESENT CONDITION _____

HAVE YOU RECEIVED ANY TREATMENT WITHIN THE LAST YEAR?

☐ YES

☐ NO

TYPE OF TREATMENT: _____

NAME AND ADDRESS OF PHYSICIAN AND/OR HOSPITALS VISITED WITHIN LAST YEAR

UNDER PRIVACY ACT OF 1974, THE INFORMATION IS VOLUNTARY

APPENDIX C

DEERS CORRESPONDENCE



DEPARTMENT OF THE ARMY
WALTER REED ARMY MEDICAL CENTER
WASHINGTON, D.C.

46

PSHL-CS

1 December 1982

Maj. Jerry L. Scott
DEERS Program Office
OASD(HA) Rm. 3E341
The Pentagon
Washington, D.C. 20301

Dear Maj. Scott:

Enclosed is a sample list of 200 Walter Reed Army Medical Center Tumor Registry patients lost to follow-up. Please provide the Tumor Registry with any addresses the DEERS Program has for these patients. It would also be very helpful to know if any of these patients have died. If it is possible for this sample, please tell us the current status of the patient; i.e., active duty or retired.

Any information or help you can provide will be greatly appreciated.

Sincerely,

Kathryn P. Deuster

KATHRYN P. DEUSTER
Major, ANC
Administrative Resident

Enclosure



OFFICE OF THE SECRETARY OF DEFENSE

DEERS PROGRAM OFFICE

47

8 April 1983

DEERS
SUPPORT OFFICE

MEMORANDUM FOR HEADQUARTERS, WALTER REED ARMY MEDICAL CENTER, (ATTN:
HSHL-CS - MAJ. DEUSTER), WASHINGTON, DC 20012

SUBJECT: DEERS Information

This is a followup to my memorandum of 15 March 1983.

The list includes both new responses and the responses on our 15 March memo.

We should complete the research within 10-15 days.

Thomas A. Grimes
LCDR, MSC, USN
Chief, Field Support Division
DEERS Support Office

Enclosure



OFFICE OF THE SECRETARY OF DEFENSE

DEERS PROGRAM OFFICE

48

15 March 1983

DEERS
SUPPORT OFFICE

MEMORANDUM FOR HEADQUARTERS, WALTER REED ARMY MEDICAL CENTER, (ATTN:
HSHL-CS - MAJ. DEUSTER), WASHINGTON, DC 20012

SUBJECT: DEERS Information

This is an initial response to your letter of 1 December 1982 requesting information on Tumor Registry, patients list to follow.

Since your request deals with specific individuals it has required a great deal of manual research. Enclosed is the first part of our research. The individuals listed were either not found (separated prior to 30 June 82) or are deceased. We are currently running the "not founds" against another file to see what information we can find for you. When the "day" of death is available I have shown it, otherwise only the month and year of death is provided. (See attached).

As I indicated on the phone last week this is an ideal use of DEERS. However, we are still several weeks away from being able to provide the information in a timely manner. Ideally you should be able to use the DEERS terminal within your health care facility for a majority of the information you need.

We are currently working on addresses for the remainder of the individuals. This involves using several manual and automated files.

Thomas A. Grimes
LCDR, MSC, USN
Chief, Field Support Division
DEERS Support Office

Enclosure

APPENDIX D

DEERS SAMPLE

DEERS SAMPLE

Sample size: 200

Names processed (December 1982 - April 1983): 161 (80.5 percent).

Addresses found: 103 (51.5 percent)

Overseas addresses: 14 (7 percent)

Deceased patients: 23 (11.5 percent)

Names/social security numbers not found in the DEERS
system: 35 (17.5 percent)

Follow-up letters returned because DEERS address was
incorrect: 12

Successful follow-up with the DEERS addresses: 60

APPENDIX E

WRAMC FOLLOW-UP FORM



DEPARTMENT OF THE ARMY
WALTER REED ARMY MEDICAL CENTER
WASHINGTON, DC 20307
May 15, 1900

52

SECTION OF

The Tumor Registry

The Walter Reed Army Medical Center Follow-Up Unit (Tumor Registry) maintains a complete and permanent record of all their patients who at any time have had a tumor diagnosis. We have a continuing interest in your progress and welfare and plan to correspond with you annually.

Although you may be presently under the care of a physician, this office is not always made aware of this in a timely fashion. If you have not been seen by a physician in the past year, we would urge at least an annual check-up.

Would you kindly fill in the information requested on this enclosed confidential questionnaire. Please feel free to make any additional comments you wish to make in reference to your condition.

Your prompt reply is appreciated.

Sincerely,

2 Encl
1 Questionnaire
1 Privacy Act Statement



DEPARTMENT OF THE ARMY
WALTER REED ARMY MEDICAL CENTER
WASHINGTON, D.C. 20012

53

REPLY TO
ATTENTION OF:

From: Walter Reed Army Medical Center
Follow-Up Unit (Tumor Registry)

HSW-SR

TO:

Name of Doctor(s) or Clinic(s) who presently follow you for your tumor condition: _____

Date and place of most recent visit for this condition: _____

Your condition at this time:

- ☐ No evidence of tumor
☐ Tumor present
☐ Not sure

Non-military address where mail will always reach you: _____

please notify us of any change in your personal address, both present and future:

(Signed) (Date)

Comments: _____

PRIVACY ACT STATEMENT – HEALTH CARE RECORDS

THIS FORM IS NOT A CONSENT FORM TO RELEASE OR USE HEALTH CARE INFORMATION PERTAINING TO YOU

1 AUTHORITY FOR COLLECTION OF INFORMATION INCLUDING SOCIAL SECURITY NUMBER (SSN)

Sections 133, 1071-87, 3012, 5031 and 8012, title 10, United States Code and Executive Order 9397.

2 PRINCIPAL PURPOSES FOR WHICH INFORMATION IS INTENDED TO BE USED

This form provides you the advice required by The Privacy Act of 1974. The personal information will facilitate and document your health care. The Social Security Number (SSN) of member or sponsor is required to identify and retrieve health care records.

3 ROUTINE USES

The primary use of this information is to provide, plan and coordinate health care. As prior to enactment of the Privacy Act, other possible uses are to: Aid in preventive health and communicable disease control programs and report medical conditions required by law to federal, state and local agencies; compile statistical data; conduct research; teach; determine suitability of persons for service or assignments; adjudicate claims and determine benefits; other lawful purposes, including law enforcement and litigation; conduct authorized investigations; evaluate care rendered; determine professional certification and hospital accreditation; provide physical qualifications of patients to agencies of federal, state, or local government upon request in the pursuit of their official duties.

4 WHETHER DISCLOSURE IS MANDATORY OR VOLUNTARY AND EFFECT ON INDIVIDUAL OF NOT PROVIDING INFORMATION

In the case of military personnel, the requested information is mandatory because of the need to document all active duty medical incidents in view of future rights and benefits. In the case of all other personnel/beneficiaries, the requested information is voluntary. If the requested information is not furnished, comprehensive health care may not be possible, but CARE WILL NOT BE DENIED.

This all inclusive Privacy Act Statement will apply to all requests for personal information made by health care treatment personnel or for medical/dental treatment purposes and will become a permanent part of your health care record.

Your signature merely acknowledges that you have been advised of the foregoing. If requested, a copy of this form will be furnished to you.

SIGNATURE OF PATIENT OR SPONSOR

SSN OF MEMBER OR SPONSOR

DATE

DD FORM 2005
1 FEB 76

PREVIOUS EDITION IS OBSOLETE

☆ GPO : 1980-665-141-1037

APPENDIX F

LETTER SAMPLE

LETTER SAMPLE

<u>Patient</u>	<u>Residency</u>	<u>No. of Letters</u>	<u>Successful</u>	<u>Total Cost</u>
1	Florida	2	No	\$1.3466
2	Maryland	2	No	1.3466
3	New York	1	Yes	.8733
4	Virginia	2	No	1.3466
5	New Jersey	2	No	1.3466
6	Tennessee	2	Yes	1.5466
7	New York	2	Yes	1.5466
8	Pennsylvania	1	Yes	.8733
9	Maryland	2	No	1.3466
10	Virginia	2	No	1.3466
11	North Carolina	2	Yes	1.5466
12	Virginia	1	Yes	.8733
13	Pennsylvania	2	Yes	1.5466
14	Virginia	1	Yes	.8733
15	New Jersey	1	Yes	.8733
16	Maryland	2	No	1.3466
17	Maryland	2	No	1.3466
18	Virginia	1	Yes	.8733
19	New Jersey	1	Yes	.8733
20	Maryland	2	No	1.3466
21	Alabama	2	Yes	1.5466
22	New Jersey	2	No	1.3466

<u>Patient</u>	<u>Residency</u>	<u>No. of Letters</u>	<u>Successful</u>	<u>Total Cost</u>
23	Virginia	2	No	\$1.3466
24	North Carolina	1	Yes	.8733
25	New Jersey	2	No	1.3466
26	New Jersey	1	Yes	.8733
27	Maryland	1	Yes	.8733
28	North Carolina	2	Yes	1.5466
29	Virginia	2	Yes	1.5466
30	Pennsylvania	1	Yes	.8733
31	Florida	1	Yes	.8733
32	Virginia	2	No	1.3466
33	Kentucky	1	No	.8533
34	Virginia	1	No	.8533
35	Massachusetts	1	No	.8533
36	New Jersey	2	Yes	1.5466
37	Virginia	1	Yes	.8733
38	South Carolina	1	No	.8533
39	Virginia	2	No	1.3466
40	Maryland	1	Yes	.8733
41	Virginia	1	Yes	.8733
42	Kentucky	2	No	1.3466
43	District of Columbia	1	Yes	.8733
44	Virginia	2	Yes	1.5433
45	Virginia	2	No	1.3466

COST OF LETTERS

Average time required to prepare a single letter was 3 minutes.
Average labor cost per minute was 0.1216.
Average labor cost per letter was 0.3648.

The cost of 3 forms per letter was 0.0885.
The cost of 2 envelopes per letter was 0.0200.
The cost of postage per mailed letter was 0.2000.
The cost of postage for each completed form returned was
another 0.2000.

The total cost of all letters mailed was \$65.1122.
Cost per successful letter follow-up was \$1.9731.*

*85 letters were mailed.
33 successful follow-up contacts were accomplished.

APPENDIX G

TELEPHONE SAMPLE

TELEPHONE SAMPLE

<u>Patient</u>	<u>Residency</u>	<u>Attempts</u>	<u>Successful</u>	<u>Total Cost</u>
1	Virginia	1	No	\$0.3332
2	Virginia	1	No	.3332
3	New York	1	No	.6448
4	New York	1	No	.3332
5	Maryland	1	Yes	.6980
6	District of Col.	1	Yes	1.1844
7	Michigan	2	No	1.258
8	District of Col.	1	Yes	.4548
9	Maryland	1	Yes	.6980
10	North Carolina	1	Yes	2.008
11	Maryland	1	No	.4548
12	Virginia	1	Yes	2.0612
13	South Dakota	6	Yes	2.616
14	District of Col.	1	Yes	.3332
15	Virginia	2	Yes	3.3344
16	South Carolina	1	Yes	1.6064
17	Virginia	6	No	.7296
18	Maryland	2	Yes	.5764
19	Florida	1	Yes	2.008
20	Maryland	1	No	.4232
21	Virginia	5	No	.7296
22	Michigan	1	No	.3332

<u>Patient</u>	<u>Residency</u>	<u>Attempts</u>	<u>Successful</u>	<u>Total Cost</u>
23	South Carolina	1	Yes	\$1.6064
24	Virginia	1	No	1.538
25	Maryland	4	No	.7880
26	Maryland	1	Yes	.5764
27	Maryland	1	No	.4232
28	Maryland	1	Yes	1.2048
29	New Jersey	4	Yes	1.6064
30	Virginia	1	Yes	2.8112
31	Maine	1	No	.3332
32	District of Col.	1	No	.4548
33	Maryland	1	No	.3332
34	South Carolina	1	No	.3332
35	Maryland	3	No	.968
36	Virginia	1	Yes	4.016
37	Virginia	1	No	.4548
38	North Carolina	2	Yes	1.6064
39	Maryland	4	Yes	1.6064
40	Georgia	1	Yes	2.8112
41	Michigan	3	No	.6448
42	South Carolina	5	No	.7296
43	New Jersey	1	No	.6132
44	North Carolina	2	Yes	1.7280
45	New York	3	Yes	1.448
46	Pennsylvania	2	Yes	1.4164

<u>Patient</u>	<u>Residency</u>	<u>Attempts</u>	<u>Successful</u>	<u>Total Cost</u>
47	Georgia	1	Yes	\$2.008
48	Maryland	1	No	.4232
49	District of Col.	1	Yes	.6980
50	District of Col.	2	Yes	.9248
51	New Jersey	1	No	.3332
52	Virginia	1	Yes	.9248
53	District of Col.	1	No	.3332
54	District of Col.	1	No	.3332
55	Virginia	1	No	.3332
56	Maryland	1	No	.3332

COST OF TELEPHONE CALLS*

Average labor cost per minute was 0.1216.

The cost of a local call was 0.0900.

The cost per minute or fraction thereof for a long distance call was 0.2800.

The cost of operator assistance was 0.0900.

The total cost of all telephone calls was \$59.1816.

Cost per successful telephone follow-up was \$2.11**

*Based on WATS costs provided by Ginny Hughes, Communication Specialist for Defense Telephone Agency, Washington, D.C.

**94 phone calls were made.

28 successful follow-up contacts were made.

APPENDIX H

COMBINATION LETTER AND TELEPHONE SAMPLE

COMBINATION OF LETTER & TELEPHONE

<u>Patient</u>	<u>Residence</u>	<u>Success via Letter</u>	<u>Telephone Attempts</u>	<u>Success via Telephone</u>	<u>Total Cost</u>
1	Virginia	Yes			\$.8733
2	Maryland	Yes			.8733
3	District of Columbia	No	6	No	1.4029
4	Virginia	No	1	Yes	1.8781
5	Maryland	No	1	Yes	3.0829
6	Maryland	No	6	No	1.4029
7	District of Columbia	No	1	Yes	1.0065
8	District of Columbia	No	1	Yes	1.8781
9	Virginia	Yes			.8733
10	District of Columbia	No	1	No	1.1281
11	District of Columbia	No	1	No	1.2497
12	District of Columbia	No	1	No	1.1281
13	District of Columbia	No	1	No	1.2697
14	Maryland	Yes			.8733
15	Maryland	Yes			.8733
16	Maryland	No	1	No	1.0065
17	Virginia	Yes			.8733
18	Alabama	No	1	Yes	1.8781
19	Pennsylvania	Yes			.8733
20	Georgia	No	1	Yes	2.2977
21	Virginia	No	1	No	.9165
22	New Jersey	Yes			.8733

<u>Patient</u>	<u>Residence</u>	<u>Success via Letter</u>	<u>Telephone Attempts</u>	<u>Success via Telephone</u>	<u>Total Cost</u>
23	Illinois	Yes			\$.8733
24	Georgia	Yes			.8733
25	New York	Yes			.8733
26	Ohio	Yes			.8733
27	Ohio	No	1	Yes	1.4765
28	Arkansas	No	1	Yes	2.6813
29	Virginia	No	1	No	1.0065
30	District of Columbia	No	1	No	1.2181
31	Maryland	No	1	No	1.0965
32	Georgia	No	1	No	.7949
33	Maryland	No	1	No	.7949
34	District of Columbia	No	1	No	1.4281
35	Connecticut	No	1	No	1.2497
36	Kentucky	No	1	No	1.2865
37	North Carolina	No	1	Yes	1.0749
38	Virginia	No	1	No	1.4081
39	Virginia	No	1	No	1.0065
40	Virginia	Yes			.8733
41	Maryland	Yes			.8733
42	New Jersey	No	1	No	1.0065
43	New Jersey	No	1	No	1.4081
44	Delaware	No	2	Yes	2.4013
45	Virginia	No	1	Yes	.9165
46	Maryland	No	1	No	1.1281

<u>Patient</u>	<u>Residence</u>	<u>Success via Letter</u>	<u>Telephone Attempts</u>	<u>Success via Telephone</u>	<u>Total Cost</u>
47	Virginia	No	1	No	\$1.0065
48	Virginia	No	1	Yes	2.2796
49	Ohio	No	1	Yes	2.6813
50	Oregon	No	1	No	1.2865
51	Virginia	Yes			.8733
52	North Carolina	Yes			.8733
53	Maryland	Yes			.8733
54	New Jersey	Yes			.8733
55	Pennsylvania	Yes			.8733
56	Maryland	Yes			.8733

COST OF COMBINATION LETTER & TELEPHONE CALLS *

Average time required to prepare a letter was 3 minutes.
Average labor cost per minute was 0.1216.
Average labor cost per letter was 0.3648.

The cost of 3 forms per letter was 0.0885.
The cost of 2 envelopes per letter was 0.0200.

The cost of postage per mailed letter was 0.2000.
The cost of postage for each completed form returned was
another 0.2000.

The cost of a local call was 0.0900.
The cost per minute or fraction thereof for a long distance
call was 0.2800.
The cost of operator assistance was 0.0900.

The total cost for all letters and telephone calls was \$69.6287.

Cost per successful follow-up was \$2.1099.**

*Telephone costs based on WATS costs provided by Ginny Hughes,
Communication Specialist for Defense Telephone Agency,
Washington, D.C.

**103 attempts were made: 56 letters and 47 telephone calls.
33 successful follow-up contacts were made.

APPENDIX I

NEW FOLLOW-UP FORM



DEPARTMENT OF THE ARMY
WALTER REED ARMY MEDICAL CENTER
WASHINGTON, D.C. 20012

71

REPORT TO
ATTENTION OF The Tumor Registry

From: Walter Reed Army Medical Center
Follow-Up Unit (Tumor Registry)

TO:

(name label)

Please provide the following information:

Social Security Number: ____ / ____ / ____ Date of Birth: _____

Sex: _____ Race: _____ Occupation: _____

Present Duty Status: ☐ Active Duty ☐ Retired ☐ Dependent

Name and address of the doctor or clinic that treated you in the past year:

Date of most recent medical visit: _____

If you have been hospitalized in the past year, please tell us where and for what purpose: _____

Please provide the address and telephone number of someone outside your household who will always know where we can contact you: _____

Your condition at this time:

☐ no evidence of tumor ☐ slight symptoms - more than 50% ambulatory

☐ tumor present ☐ slight symptoms - less than 50% ambulatory

☐ not sure ☐ bedridden

☐ condition normal

Please tell us of any change in your name and/or address: _____

Signed

Date

Comments: _____

APPENDIX J

PROJECT FINDINGS

Project FindingsResponses*

	<u>Letter Sample</u>	<u>Telephone Sample</u>	<u>Combination Letter & Telephone Sample</u>
Attempts	85	94	103
Successes	33	28	33
Failures	52	66	70

Percentages

Successes	39	30	32
Failures	61	70	68
Sample Popu- lation that responded	59	50	59

Average Cost Per Attempt

<u>Letters</u>	<u>Telephone</u>	<u>Combination Letter & Telephone</u>
0.7660	0.6296	0.6760

Average Cost Per Successful Attempt

\$1.9731	\$2.1136	\$2.1099
----------	----------	----------

*Each sample contained 56 patients.

APPENDIX K

FITZSIMONS FORM

PATIENT FOLLOW-UP INFORMATION	INSTRUCTIONS: Return this form to the Surgery Research Office, 8th Floor (West), Main Hospital Building, Fitzsimons Army Medical Center, Aurora, Colorado 80045. <i>In accordance with 10 U.S.C. 133, 1071-57, 3012, 5031 and 5013, voluntary disclosure of personal information is requested in order to maintain follow-up records to evaluate results of treatment offered at this medical center so as to plan and coordinate health care and provide optimum benefits.</i>		DATE
	PATIENT'S NAME (First, Middle, Maiden, Last)		GRADE
DATE OF BIRTH (Month, Day, Year)		PLACE OF BIRTH (City and State)	
OCCUPATION			
SPONSOR'S NAME (First, Middle Initial, Last)		GRADE	SPONSOR'S RELATIONSHIP
WIFE'S NAME (First, Middle Initial, Last)			
HOME ADDRESS (Street, City, State, Zip Code)			
<i>List two other persons (with different addresses) who will always know where you are to give us a total of three addresses through which you might be reached. This will assist us in locating you should you move from your current address.</i>			
NAME (First, Middle, Last)	ADDRESS (Street, City and State)	RELATIONSHIP TO YOU	
1.			
2.			
SMOKING HISTORY			
HAVE YOU EVER SMOKED <input type="checkbox"/> YES <input type="checkbox"/> NO	HOW MANY YEARS	AVERAGE PER DAY	
CURRENT ADDRESS (If different than above)			
THIS SPACE FOR USE OF SURGERY RESEARCH OFFICE			

APPENDIX L

MILITARY FOLLOW-UP SOURCES

Military Locator Sources

ARMYActive Duty

Commanding Officer
Allotments and Deposits Operations
Finance Center, US Army
Indianapolis, IN 46249

Retired

Commander
USAFC
ATTN: Retired Pay Division
Indianapolis, IN 46249

Active Duty Enlisted

Commander
USAERC
ATTN: PCRE-RL
Fort Benjamin Harrison, IN 46249

Army Locator

Commanding Officer
US Army Personnel Service
Support Center
Fort Benjamin Harrison, IN 46249

Discharged

Commanding Officer
Army Records Center, TAGO
9700 Page Blvd.
St. Louis, MO 63132

Reserves

Commander
RCPAC ATTN: PSE-VS
9700 Page Blvd.
St. Louis, MO 63132

Deceased

National Personnel Records Center
General Services Administration
9700 Page Blvd.
St. Louis, MO 63132

Active Duty Officers

Commander
USA MILPERCEN
ATTN: DAPC-PAR-SL
200 Stovall St.
Alexandria, VA 22332

AIR FORCE

Directorate of Administrative Svcs.
Headquarters, US Air Force
Washington, D.C. 20330

Personnel Records Division
The Adjutant General's Ofc.
3511 S Carlyn Spring Road
Falls Church, VA 22041

Active Duty

Commander
USAFMPC (AFPMdra)
Randolph Air Force Base
San Antonio, TX 78148

Retired

Commander
AFAFC
ATTN: Retired Pay Division
Denver, CO 80279

AIR FORCE (Cont.)Separated

Director
Air Force Records Center
9700 Page Blvd.
St. Louis, MO 63132

NAVY AND MARINE CORPS

Chief, Bureau of Naval Personnel
Department of the Navy
Washington, D.C. 20360

Retired

Commander
Navy Finance Center
ATTN: Retired Pay Division
Cleveland, OH 44101

Active Duty

Commander
Navy Finance Center
Cleveland, OH 44114

Reserve Duty

Naval Reserve
Personnel Center
4400 Dauphine St.
New Orleans, LA 70149

TDRL Section
Department of Navy
Naval Reserve Personnel Section
4400 Dauphine St.
New Orleans, LA 70149

USN Record Mgmt Center
ATTN: DPRB
9700 Page Blvd.
St. Louis, MO 63132

Discharged or Deceased

National Personnel Center
General Service Administration
9700 Page Blvd.
St. Louis, MO 63132

COAST GUARD

Commandant
Coast Guard Finance Center
400 7th Street, S.W.
Washington, D.C. 20590

BIBLIOGRAPHY

BIBLIOGRAPHY

Books

- American Cancer Society. The Hospital Cancer Registry. New York: American Cancer Society, Inc., 1966.
- American College of Surgeons. Cancer Program Manual. Chicago: American College of Surgeon's Commission on Cancer, 1981.
- American College of Surgeons. Cancer Program Manual: A Supplement on the Tumor Registry. Chicago: American College of Surgeon's Commission on Cancer, 1981.
- American College of Surgeons. Guidelines for Cancer Care. Chicago: American College of Surgeon's Committee on Guidelines for Cancer Care, undated.
- Daniel, Wayne W. Biostatistics: A Foundation for Analysis in the Health Sciences. New York: John Wiley & Sons, 1978.
- Department of Defense. DOD 1341.1M DEERS Program Manual. Washington, D.C.: May 1982.
- MacLennan, Robert, et al. Cancer Registration and its Techniques. Lyon: World Health Organization's International Agency for Research on Cancer, 1978.
- Selby, Samuel M., ed. CRC Standard Mathematical Tables, 19th ed. Cleveland, Ohio: The Chemical Rubber Co., 1971.
- Shambaugh, Evelyn M., ed. Self-Instructional Manual for Tumor Registrars, Book One. Washington, D.C.: National Institutes of Health, 1980.

Periodicals

- Baker, Harvey W., et al. "Why Follow-Up the Cancer Patient?" The American College of Surgeons. Undated.
- Campbell, Nancy Lee. "Morton's Cancer Registry is Hospital Based Program." The Abstract 8, No. 3 (February 1982), p.14-15.
- Clemmessen, Johannes, "Uses of Cancer Registration in the Study of Carcinogenesis," Journal National Cancer Institute 67, No. 1 (July 1981):5-13.

BIBLIOGRAPHY (Cont.)

- Clive, Rosemarie and James, Brent. "CanSur: Modern Data Management for Improved Cancer Patient Care." Bulletin, American College of Surgeons. 66 No. 9 (September 1981):14-16.
- Chapman, Dawnelle. "Patient Wallet Card." The Abstract 7, No. 1 (November 1980):12.
- Feigl, P., et al. "U.S. Centralized Cancer Patient Data System for Uniform Communication Among Cancer Centers," Journal National Cancer Institute. 67, No. 5 (November 1981): 1017-1024.
- Fleming, Irvin D. and Summer, Sue. "The Hospital Cancer Program: Its Benefit to Patients." Bulletin, American College of Surgeons, 65 No. 9 (September 1980):10-13.
- Greenberg, E. Robert, et al. "Measurement of Cancer Incidence in the United States: Sources and Uses of Data." Journal National Cancer Institute 68, No. 5 (May 1982):743-750.
- Hurst, Marilyn C. "Presidential Message." The Abstract 9, No. 1 (August 1982):3-4.
- Lawrence, Walter Jr. "Hospital Cancer Programs and Registries: What Good are They?" Virginia Medical 107, No. 10 (October 1980):708-709.
- Meyer, Kenneth K. "The Tumor Registry's Values to Hospital Administration." The Abstract 4, No. 3 (December 1977): 3-4.
- Miller, A.B., et al. "Reporting of Cancer Treatment." Cancer 47, No. 1 (January 1, 1981):207-214.
- McKenna, Robert J. "Goals for a New Decade." Bulletin, American College of Surgeons 65 No. 9 (September 1980):5-7.
- Priest, Stephen L., et al. "Various Experts Work to Shape Computerized Tumor Registry." Hospitals 52 No. 2 (January 16, 1978):69-72.
- Russe, Henry P. "The Hospital Cancer Program: Its Values to the Administrator." Bulletin, American College of Surgeons 65 No. 9 (September 1980):8-10.

BIBLIOGRAPHY (Cont.)

Russe, Henry P. and Peterson, Vida M. "The Benefits of a Hospital Cancer Program." The Hospital Medical Staff 11, No. 2 (February 1982):12-14.

Schmitz, Robert L. "Patterns-of-Case Studies: Results and Consequences." Bulletin, American College of Surgeons 65 No. 9 (September 1980):20-22.

Schweitzer, Robert J. "The Surgeon's Role in Cancer Care." Bulletin, American College of Surgeons 64 No. 9 (September 1979):3-5.

Shambaugh, Evelyn. "President Notes Accomplishments, Goals." The Abstract 7 No. 1 (November 1980):5-8.

Smart, Charles R. "The Commission of Cancer." Bulletin, American College of Surgeons 65 No. 9 (September 1980):3-4.

Thiele, B.E. "Utilizing the Tumor Registry." The Abstract 5, No. 4 (July 1978):1.

Other

Defense Enrollment Eligibility Reporting System. DEERS Fact Sheet April 1983.

END

DATE
FILMED

DEC.

1987